

# Reflections on Ethics and Humanity in Pediatric Neurology: the Value of Recognizing Ethical Issues in Common Clinical Practice

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Published online: 28 March 2017  
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**Abstract** Our goals in this reflection are to (i) identify the ethical dimensions inherent in any clinical encounter and (ii) bring to the forefront of our pediatric neurology practice the myriad of opportunities to explore and learn from these ethical questions. We highlight specifically Beauchamp and Childress's principles of biomedical ethics. We use the terms *ethics in common clinical practice* and an *ethical lens* to remind people of the ubiquity of ethical situations and the usefulness of using existing ethical principles to analyze and resolve difficult situations in clinical practice. We start with a few common situations with which many of us tend to struggle. We describe what we understand as *ethics* and how and why developments in technology, novel potential interventions, policies, and societal perspectives challenge us to think about and debate ethical issues. Individual patients are not a singular population; each patient has their own unique life situations, culture, goals, and expectations that need to be considered with a good dose of humanity and humility. We believe that using an ethical lens—by which we mean making an explicit effort to identify and consider these issues openly—will help us to achieve this goal in practice, education, and research.

**Keywords** Morality · Clinical ethics · Neurodisability · Children · Education · Research

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Topical Collection on *Pediatric Neurology*

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## Background

The authors of this paper (a pediatric neurologist (GMR) and a developmental pediatrician (PLR)) have devoted their professional careers to clinical and research work with children and youth with neurological and developmental impairments, and their families. From 2013 to 2016, we had the privilege of collaborating with colleagues from several countries, and disciplines, to co-edit a book titled *Ethics in Child Health: Principles and Cases in Neurodisability* for Mac Keith Press [1•]. In this essay, we reflect on what we have learned and what we hope others will find meaningful, about bringing to the foreground ideas that we have come to recognize as ethical issues of common clinical practice in our field. We offer perspectives rather than answers or formulae, and end with some thoughts about how these apparently self-evident but often overlooked issues can be more formally identified, discussed, and studied in daily clinical practice, in the training of all health care professionals worldwide, and in health services and policy research.

## Introduction

Has this ever happened to you?

- You wonder how to prioritize incoming referrals...
- You wonder how to approach concerned families for the first time...
- You desire to improve how to formulate, and explain to families, issues such as diagnosis, prognosis, evidence-based medicine, and potential interventions ...
- You wish to learn how best to deliver *bad news*...
- You wonder how to respect cultural variations and values...

- You wonder how best to respond to patients' questions seeking advice or endorsement for alternative, "natural," and complementary therapies...
- You wonder how to deal with individuals who comply poorly with their medication regimen, or with families who do not keep their appointments...
- You wonder whether you can lie on behalf of a patient...
- You wonder whether or how you can use placebos to alleviate pain and suffering...

As professionals immersed in the field of childhood neurodisability, we have come to recognize the vast range of common situations and challenges to which we hopefully apply rules of *good clinical practice*, but which we usually do not consciously and formally identify as matters that deserve explicit *ethical* thought and attention. This is probably because these many issues are not experienced or thought of as being dire enough to be referred to the courts or to formal hospital ethics committees. It may also reflect the fact that we do not pause to make the ethical perspective explicit when analyzing a clinical situation. However, as one considers the everyday challenges that all clinicians face, it becomes easy to visualize both the interplay between good clinical practice and ethical issues, and the value of shining a light beam specifically and openly on the *ethical* components of issues such as the examples set out above.

### Contemporary Understandings of *Ethics*

As in so many areas of the field of health care, emerging ideas continue to be parsed and refined as people explore them (examples include the continuing discussions about the many meanings of *quality of life* [2]). This evolution in language and concepts is equally compelling in the area of bioethics—the convergence of dialogs between medical practice and the discipline of ethics. The authors' colleague and co-editor of the ethics book [1••] Dr. Eric Racine is a professional ethicist who helped us begin to understand the language and concepts that should inform clinical and ethical thinking and behavior [3••]. Here, we outline briefly some of his key concepts that we hope will be of use to others.

- Racine notes the important distinction between *moral* perspectives, a term he uses to refer to behavior and situations, and *ethics*, which refers to the discipline concerned with moral questions and that discipline's attempt to provide a reasonable process of problem resolution to moral problems. Expressed succinctly by Racine, "Ethics takes morality as its object." (p. 27)
- *Dilemmas* refer to situations (problems) in which there are two (or perhaps more) mutually exclusive options requiring consideration through an *ethics lens*. We use this

phrase to refer to the processes by which we make an active effort to identify and formally consider these issues as having an *ethical* dimension. One might colloquially think of these as examples of *hard questions*: there are no easy answers! (See the earlier list of questions.)

- These situations (and the moral questions they raise) can challenge us as professionals because they force us to consider our own deeply held principles and beliefs, often outside the comfort zone of our usual knowledge bases and experiences. To quote Racine once more, "To fully consider these issues, one needs humility, as well as open-mindedness and a propensity to reflect on one's own beliefs and actions." [3••], p 28.

Readers seeking a more in depth understanding of these issues will find Racine's lucid writings very helpful.

Philosopher Tom Beauchamp and philosopher-theologian James Childress have articulated and analyzed in depth perhaps the best-known approach in the Western world to formulating an approach to ethical reasoning to resolve ethical dilemmas in clinical care. The *four principles* of modern biomedical ethics are as follows: *autonomy* (the view that each person is an individual worthy of respect), *beneficence* (doing good), *non-maleficence* (doing no harm), and *justice* (fairness regardless of a person's circumstances). Each of these principles is considered equally important and none trumps another [4].

Alternative approaches to aid clinicians achieve ethical resolutions are less familiar to health professionals but are well explained in several ethical texts, e.g., [3••, 5]. For example, *clinical ethics* developed by Jonsen et al. [5] focuses on clinical utility. This approach recognizes four elements, namely *medical indications*, *quality of life*, *patient preferences*, and *contextual features*, that provide the *essential structure of a clinical encounter* that can be applied in many situations like the clinical scenario below. Here, relevant ethical principles (essentially the same as those of Beauchamp and Childress [4]) are considered, in order to determine which are most important and guiding in the specific clinical situation [5], p. 3. Through this analysis, the clinician is able to decide which decision would be ethically optimal by comparing what is good ethical practice in this case versus other cases; decisions made in similar and different cases are compared. Racine [3••] notes that this is analogous to case law in jurisprudence, applied to ethical reasoning.

*Pragmatism* is another recent integrative ethical approach to help clinicians and families engage toward resolution of ethical situations in a series of small steps (see [3••, 6]).

### Why Ethics?

The concept of ethics in medicine has been with us for millennia, with recent updates often based either on court

decisions provoked by novel biological and technological breakthroughs or by gross mishandling of individuals or specific populations [7]. However, ethical questions can be daunting, in particular because, as noted above, they challenge us on our core principles and our most profoundly held moral beliefs about ourselves and others. By sharpening our ability to recognize the ethical aspects and humanity relevant to daily healthcare issues experienced by individual families or specific populations (e.g., children with neurodevelopmental impairment), we believe we will be able to improve our capacity and capability to identify new opportunities to address and potentially resolve difficult situations in the office and on the ward. These considerations are analogous to applying *systems theory*, which implies that the more complex a system becomes (in this case the ethical situation or question) the more opportunities become available to intervene. In addition, system theory helps in terms of recognizing or identifying emerging patterns and rules [8].

### Why the Current Interest in Ethics?

Despite remarkable technological progress in contemporary biomedicine, impairment, and disability will always be part of the human condition. One factor among many that contributes to this reality is that with increasing longevity across many parts of the world, and with the successful management of many previously fatal childhood-onset conditions that now become chronic illnesses, more and more people are living long lives associated with functional limitations. According to the CDC in 2013 [9], approximately one in five US adults reported any type of disability (impairment), which translates into the remarkable fact that people with disabilities are the largest minority group in the USA [10]. Given this reality, and the equally important idea that there is much that even contemporary medicine cannot fix, a major goal of healthcare will continue to focus on how to improve the life trajectories, life quality, and functioning of affected individuals worldwide [11]. It is essential that we be able to do so in ways that can stand up to careful ethical scrutiny.

In today's world, we increasingly experience unexplored challenges. One example is the media hype about novel biomedical breakthroughs, offering the impression of forthcoming or even imminent cures for many neurological maladies. The increasing excitement about stem cell therapies for children with neurodisabilities is a recent example of the need for academically strong evidence of efficacy, safety, and generalizability of effects, coupled with ethically sound processes by which to handle this tsunami of pressure to adopt new interventions uncritically. Equally pervasive are media reports about the successful alleviation of suffering with *natural* or *organic* products in individuals whose problems seem otherwise intractable. Offering this sort of great hope may be appropriate in selected situations

but can otherwise be vastly misleading and create ethical challenges for practitioners and clinical programs when everyone is striving to practice *evidence-based medicine*. The *technological imperative* is another example of the potential for uncritical use of novel technological investigations, either because they are available or because of our own curiosity, often undertaken without an honest ethical exploration or detailed informed consent and assent [12].

Fortunately, we are also observing a gradual shift in our healthcare provision by expanding our perspectives beyond simply trying to *fix* patients with chronic conditions toward a broader biopsychosocial conceptual approach with the adoption of novel constructs in health care such as *person- and family-centered care* and focusing on the person's self-defined *quality of life* see also [13]. As healthcare professionals, we are also starting to adjust our views along a more realistic meaning of health that incorporates the personal perspectives of the ever-growing number of individuals with chronic conditions [14]. These perspectives, among others, evolve based on viewing health through the biopsychosocial lens of each individual's functioning, abilities, personal goals and expectations. These developments are directly linked to the societal progress with the enshrining the rights of children [15] and of persons with disabilities [16] by the United Nations and many individual countries. The emergence of effective patient and child-and-family advocacy groups, and the recommendations for knowledge translations, are additional by-products of these developments. Applying these novel developments will help to raise the moral standards of our daily clinical practice.

### What Do We Mean by *Common Clinical Practice Ethics*?

It may seem obvious that there are ethical dimensions to all human behavior. As clinicians, we can recognize the ubiquity of ethical realities: *every* encounter has ethical elements, to which we refer briefly in this paper. Thinking of *ethics* as a first step—using an *ethical lens* through which to refract every situation—provides an opportunity to look more deeply and broadly into all our individual behaviors as clinicians. Moving beyond the individual patient encounter, we can identify ethical dimensions of the programmatic decisions we make on behalf of groups of patients (as described in the scenario below, concerning those who are often thought of as *hard-to-serve* and who may too easily be dismissed from care, despite our mantra of being *family-centered*). Equally, in advising regional authorities and policy-makers, there are ethical considerations to be recognized; for example, do policies unfairly advantage some *special* populations at the expense of others (consider how large a portion of the childhood disability resource is directed solely to autism).

Thus, we are interested to identify and explore what we think of as the *ethics of daily clinical life*—issues and challenges that, as noted earlier, are usually not actively thought about or discussed in courts or ethics committees because they are not perceived as important enough to require this kind of expert consideration. In this paper, we want to move the discussion from *familiar-and-recognizable-when-identified* to *front-of-mind-and-worthy-of-clinical-and-academic-analytic-discussion*. We propose that we all can learn how to anticipate and make *ethics* explicit as a guiding principle, and encourage people to use the words and concepts of *ethics* in our considerations and discussions with colleagues and families.

### Consider three clinical examples:

*First scenario:* The clinic administrator informed us that David R had been a no-show for the third time. David is a 10-year old boy with intractable seizures, cognitive, and behavioral impairments. We suspected that David suffered from an as-yet unidentifiable genetic epileptic encephalopathy but had not had the opportunity to explain to the family why we would recommend genetic evaluation. His mother called in only to request renewal of the prescription for anti-seizure medication or after David had experienced a prolonged seizure. Whenever we received these phone messages we wondered whether his condition was actually deteriorating or whether David did not regularly receive his medication.

We consider ourselves to be empathic clinicians who support patients and their families under our care to achieve their best quality of life and functioning. We also try to empower the person's abilities rather than focus on their functional impairments.

What were our options with David and his family without jeopardizing his care, while at the same time ensuring that all the patients booked for our clinic will in fact arrive and get our full clinical attention? Common sense or common morality, which often helps us in decision-making, failed us in the current context. We referred to the literature to identify similar situations and punched in the words "ethics," "clinic attendance," and related terms but were unable to identify any relevant article with guidelines on how to act under similar situations. Our subsequent step was to apply known ethical principles.

We wanted to start with Beauchamp and Childress's four principles of modern biomedical ethics [4]. But would applying these principles brings us closer to a satisfactory resolution? For example, whose autonomy or rights come first—those of the child, the parent, or society? This question could not be easily answered because we knew very little about the social and cultural details of this family. The principle of beneficence demands doing good and is closely related to the principle of non-maleficence (do not harm). As such, would reporting the family to child social services and requesting

them to explore the family situation advance the best interest of the child? And how would the principles of justice and equity fit into the situation to advance the child's cause? It became obvious that the situation could not be solved within the hospital walls, so we invited community-based social services to assess the situation in a non-threatening way.

*Second scenario:* Seeing a family in a pediatric neurology consultation for the first time can be a challenging and daunting act that may extend beyond the narrow territory of the initial biomedical complaint. This reality is illustrated by the situation of JR, a 2-year-old child with new onset of seizures. JR's parents, in their late 30s, described the events that precipitated their visit and produced a brief video clip of a nocturnal event that appeared to be a genuine seizure. From the start of my encounter, I felt a tension in the room, which I attributed to parental anxiety. I decided initially to proceed carefully with my inquiry to capture all the details that might help me identify an epileptic syndrome and a possible underlying etiology.

In a scenario like this there are a myriad of issues to discuss with the family: What is epilepsy? Can we uncover an underlying cause? What can we do about it? What management plan should we recommend? What will the prognosis likely be? How do we respond to the questions about whether the child will develop normally, or whether a parent should now sleep with him? What precautions do the parents need to follow? The professional recommendation to inform parents of the potential risk of sudden unexpected death in epilepsy or SUDEP during the first clinic visit was front of mind. When and how was I going to disclose this subject [17, 18]?

I wondered whether the basic information was already overwhelming for the parents. How were they going to absorb all of it, both cognitively and emotionally? Where and when should the SUDEP disclosure "seeds" be planted? The consultation was coming to a close. I felt that it was "now or never" to discuss SUDEP and that I would fail the family if I postponed this disclosure to another appointment. I also believed that postponement might negatively impact our mutual relationships and future trust-building. I recognized that I faced an urgent ethical situation and needed to find a resolution before the consultation was over. I felt that using basic ethical principles might assist me in developing a reasonable analysis to the dilemma. But how could I decide about critical principles explored by Beauchamp and Childress—issues such as whose autonomy is at stake here, and whether the parents want to know at all about SUDEP at this point? How could I decide whether I was doing more good than harm to the family's quality of life, or what was meant by fairness and justice in the current situation? I realized that I could not answer these questions with any depth.

Reflecting on these questions, in a scenario like this, becomes the critical element in my analytical deliberations. Bereaved parents, patients, and advocacy groups have asserted their autonomy by requesting that discussion on SUDEP should begin during the first consultation by the

managing neurologist—an approach that I need to respect. In addition, it becomes apparent that I need to know and understand the family. *Quoting Sir William Osler: “It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.”* Thus, I needed to engage in the family’s narrative, learn about their values, culture, goals, expectation, and mental health. Having this information might guide me on how to introduce and explain the topic of SUDEP without producing excessive emotional strain. It might take extra time during this initial visit, but it seemed to be an appropriate long-term strategy. Fortunately, I had a social worker on our team who agreed to help me explore this family’s narratives. Better understanding the family was essential, but did it solve my personal communication challenges? The disclosure of SUDEP needed to be honest, empathetic, and adapted to the family.

Heath [19] reminds us that “evidence-based medicine” tempts us to try to describe people in terms of research data that are expressed in numbers. However, in her words “...as clinicians, we remain unsure of the language. Words are infinitely malleable and adaptable and can communicate much more than numbers. Words are essential to help patients to understand what is happening to them and what might help. Only with words can we forge trust, relieve fear, and find meaning”. I was finally ready to discuss the topic of SUDEP in a family-specific, humane context. I gently asked the parents whether they had come across the topic termed SUDEP while surfing the Internet—and indeed they had “stumbled over it” but were too anxious to raise this issue. They primarily wanted to know whether it could be prevented and hoped for specific guidance, which I could not deliver. However, they thanked me for raising the topic in a gentle and caring manner and were looking forward to their next clinic appointment.

*Third scenario:* One day, in the Neonatal Follow-up Clinic, I met a 3-year-old child and his parents for the first time. The silent child wore two rather conspicuous hearing aids. While I talked with his parents, he sat at the children’s table, coloring, and playing appropriately with puzzles. When I asked his parents how I could be helpful, they told me that they were very concerned about their son’s behavior, which included frequent tantrums. Given the boy’s obvious impairment, I enquired about their understanding of his hearing and about his ability both to take in the world aurally and to express himself. I learned that he was significantly hearing-impaired and had no symbolic expressive “output” (words, signs, gestures, or a picture symbol system). The parents then told me that they were actively pursuing auditory verbal therapy (AVT), an approach to the boy’s issues that puts a premium on exploiting a child’s residual hearing and discourages the use of alternative modes of communication such as signs, lip reading and symbol systems [20].

Their information caused me much discomfort, and I recognized that I faced an ethical dilemma! I knew enough about

AVT to believe it to be seriously inappropriate from a developmental perspective, controversial, and of uncertain efficacy [21]. I also strongly believe that it simply is inappropriate to limit any child’s early developmental experience. I immediately had to consider whether and how to discuss my concerns with the parents, recognizing that they were very invested in what I believed to be an inappropriate and inadequate approach to their son’s developmental predicament, and that a full-frontal critique would be useless. I had to find a way to meet them half-way.

I told the parents that I had another idea for them to consider and asked permission to suggest an alternate way to think about their son’s issues—to which they agreed. From other aspects of their story, it had become apparent that the boy’s behavior was very likely related to isolation in his ‘deaf’ world, with no way to express himself. I suggested that while retention of any residual hearing was certainly a worthwhile goal, I was concerned that no one was able to access what this boy “had on his mind” and that limiting both his “intake” and “output” to aural/oral function made no sense! Were he to be offered ways to both understand the world of symbolic language (e.g., by “receiving” signs and lip-reading and pictures) and be empowered to express himself in ways that were more direct and useful than tantrums (e.g., with gestures, signs, and pictures). His parents would have important insights into his thinking and have opportunities to engage in the transactional interactions that are the essence of the “dance” between children and parents [22]. Fortunately, they were not defensive and agreed to consider these ideas.

I reflected later that the discomfort I had experienced concerned the reality that “complementary and alternative” (CAM) therapy approaches abound, and parents are often invested both financially and emotionally in these approaches. Some CAMs probably work, but I was very skeptical of this particular approach, which made absolutely no sense developmentally and was, I felt, holding the boy and his family back. Having previously challenged families unsuccessfully about AVS, I was at least able to engage in a civil conversation and offer the parents some new perspectives.

Sadly, I never learned whether this encounter changed anything!

### Situations Associated with Common Clinical Practice Ethics

We believe that every clinical encounter with, or about, a patient with a chronic condition presents issues that have an ethical dimension. As but a few illustrations, consider these examples:

- The contemporary practice of *evidence-based medicine* raises new ethical questions for all health professionals

[23]. On one side, evidence is essential, especially when we acknowledge that interventions for many pediatric neurological conditions have at best only low levels of evidence for their effectiveness [24•]. We all know that additional robust evidence is badly needed. Yet, we also need to be aware of the limitations of evidence that are neatly captured by Nagendran and colleagues [25•] whose work examined whether results from randomized trials with large effect-sizes are reproducible in follow-up studies. These authors concluded that the reproducibility of such studies should be interpreted with caution and that follow-up studies should not be discouraged. Abbasi [26], reflecting on Heath's analytical essay [19], has pointed out that even in the presence of well-researched interventions it is possible that "*a rift exists between the evidence-based medicine that guidelines ask us to deliver and the humanity that patients seek in clinical encounters. Each patient poses unique challenges that can't be boiled down to the outcome of a randomized controlled trial*". We propose that by applying an *ethical lens*, clinicians could deliver more coherent and better-balanced consultations; in other words, this *ethical* approach could bridge the potential rift between evidence and humanity.

- The nature of the relationship that a healthcare provider develops with someone who has an intractable condition can be absolutely formative in the way the patient and their family perceive and experience their reality. Even when medical interventions seem futile, supportive person-centered care will likely enhance the quality of life and well-being of that person and their family. On the other hand, communicating a sense of hopelessness about the situation—even if justified on a strictly biomedical basis—can too easily contribute to a person's further decline in both physical and spiritual well-being.
- What, then, is the ethical way to behave and do we even frame the clinical question this way? Do we *hang crepe* (and give a bleak prognosis in an effort to prepare people for the worst), or *prognosticate* about each individual's unique predicament [27]? Can we offer hope when there seems to be none [28]?
- When patients have complex conditions, there is likely to be a team of professionals working with the patient and family. The more people that are involved, the more chance there is for variations in perspectives about virtually any aspect of the patient's situation—be it defining the diagnosis and prognosis, discussing options for management, or determining clinician's roles and responsibilities.... In this kind of situation, there are risks of disagreements among professionals, patient-professional differences of opinion, and patient-and-family conflicts with one another—all of which can be considered and managed using ethical principles as well as communicative skills.

- As experts in our various fields, we may be called upon to advise policy-makers or others responsible for decisions that affect a whole community. As one personal example, there has been a considerable pressure to offer *screening* programs to improve the early detection of conditions like muscular dystrophies, autism spectrum disorder, or fetal alcohol spectrum disorder. At its best, screening is a compelling and powerful approach to the early detection and profoundly important (even life-saving) management of certain specific early-onset conditions (examples include PKU, thyroid deficiency, and galactosemia). What is less apparent to non-experts is that a number of elements of a screening program must all be in place and aligned for the programs to be effective and do more good than harm [29]. Thus, even the strongest advocates for screening need to act responsibly and ethically by challenging the good intentions of the activists with evidence-based information and not simply acceded to what *should be done* [30]. The availability of a screening test does not mean that it should be used without applying an *ethical filter* that explores all the ramifications of the issues (such as false-positive and false-negative results).

### Where Can Clinicians Turn for Guidance on Ethical Practices?

As noted by several of the authors who contributed to our recent book, virtually all professional bodies have codes of conduct and guidelines regarding ethical behavior and the management of conflict (examples cited included the American Physical Therapy Association (n.d.) Code of ethics for the physical therapist [online]; www.

[apta.org/uploadedFiles/APTAorg/About\\_Us/Policies/Ethics/CodeofEthics.pdf#search=%22ethics%22](http://apta.org/uploadedFiles/APTAorg/About_Us/Policies/Ethics/CodeofEthics.pdf#search=%22ethics%22) (accessed 11 February 2012); the American Occupational Therapy Association, Ethics Commission (2010) Occupational Therapy Code of Ethics and Ethics Standards 2010 edition. Am J Occup Ther 64: S17–S26; the American Academy of Pediatrics Committee on Bioethics (1994) Guidelines on forgoing life-sustaining medical treatment. Pediatrics 93: 532–536.) and publications by the Child Neurology Society Ethics Committee. Thus, in addition to the texts on bioethics that might be available in people's hospital libraries, there are many profession-based resources available at the click of a mouse. The challenge, of course, remains that people need to recognize and be prepared to act on the fact of an ethical dilemma when it arises.

One further observation offered by a thoughtful colleague reviewer is that none of these resources (books, codes, websites) is interactive. We believe that actual discussion

about the issues identified in this essay should also be promoted. Ethics can in theory provide the right forum.

### What Are the Educational and Training Implications of an Increased Focus on Ethics?

Over the past century, medical education has been the focus of constant development and reassessment of both content and process. A recent international task force identified *critical thinking*, *knowledge translation*, and *ethics* as the three pillars on which future education across societies should rely [31]. Just as clinical and health services researchers are expected to pursue formal training in the ethical conduct of research, it is the authors' belief that there should be an equal emphasis on the formal identification of, and training in, the ethical dimensions of all aspects of clinical practice. We believe that this should start as soon as healthcare providers in any field begin their training. Furthermore, the exposure needs to be continuous and infused into clinical teaching in the lecture hall, in the clinic, and at the bedside. In so far as ethics "refers to the discipline concerned with moral questions and that discipline's attempt to provide a reasonable process of problem resolution to moral problems" (cited above), students in all disciplines need repeated opportunities to think, talk, and act with these principles as their guide.

The mechanisms for doing this kind of exposure and training can be many and varied. They can include case scenarios for small-group discussion or the description (on paper) of real-life dilemmas that are created by teachers, discussed in tutorials, and then brought to life with the active engagement of the actual protagonists in the scenarios (a powerful experience for learners, who have in our experience often been able to identify the issues which are then shown to be real-life matters)! We can challenge learners in their clinical rotations to identify, present, and discuss an *ethical issue* associated with a clinical case with which they are involved. This latter example might include the expectation that the ethical issue be *minor*—simply to make the point that these issues are everywhere, and what may seem *minor* can still be associated with opportunities for discussion and reflection. Journal clubs provide another opportunity to review articles and discuss the ethical dimensions of the text. (In the authors' recent book, every chapter ends with a selected group of *Themes for Discussion*, presented simply as examples of the kinds of issues that can be used as a springboard for group discussion.)

### Where Do We Go Next?

As alluded to throughout this essay, we believe that educators in all fields of clinical services should formally and actively identify *ethics* as an integral component of the education and

training of all service providers. We believe that this can be accomplished in many ways. It might, for example, be important to add questions about the ethical conduct of clinical care to professional qualifying exams. Their presence there would provide a powerful endorsement of the importance of this theme to all learners.

Equally importantly, there is a crying need for scholarship in clinical ethics by frontline clinicians. Based on some work currently underway by the authors, we encounter on average 10 publications a year on ethics in neurodevelopmental pediatrics. Most of these are opinion papers (like this one), with only an average of two per year being true research papers. As noted, there are myriad opportunities for trainees to explore these issues in a scholarly manner. Doing this (and much else) from *within* the clinical settings, and involving families in identifying useful research questions, will then imbue *clinical ethics* with the same kind of academic legitimacy as is experienced by both quantitative and qualitative clinical research and is beginning to be achieved by excellent research in fields like patient-reported outcomes of quality of life and participation. We believe that the time is ripe to be bold and to carve out an active field of research and scholarship in *clinical ethics*, developed by clinicians in collaboration with experts from related fields.

**Acknowledgements** The authors wish to thank Drs. Bernard Dan from Brussels and Eric Racine from Montreal for their insightful comments and recommendations.

### Compliance with Ethical Standards

**Conflict of Interest** Gabriel M. Ronen and Peter L. Rosenbaum will receive royalties from Mac Keith Press for the book *Ethics in Child Health: Principles and Cases in Neurodisability*.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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Papers of particular interest, published recently, have been highlighted as:

- Of importance
- Of major importance

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